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ABSTRACT

The Family Support Project in Lansing, Michigan, provides a variety of family support services to help maintain severely mentally and severely multiply impaired children in their own communities, and whenever possible, in their own homes. Services offered include case management, family therapy, respite services, special needs purchases, administration, program evaluation, and a parent task force serving in an advisory capacity to project staff. Among results from 9 months of operation are that efforts to outreach families with children residing in state institutions were hindered by confidentiality and release of information regulations; that the most highly used services were those of local schools; and that three basic need areas expressed by families were parent to parent support as early as possible, specialized training opportunities for family and staff who care for children, and additional short and long term community residential alternatives. Other findings related to project goals are that: the proportion of families maintaining their children in the community or in their own homes was not increased; eligible families received a number of support services not previously available to them; and the levels of intervention and assistance to individual families were not reduced. Among recommendations were that an official emergency respite service system be established as part of an agency wide on-call system in response to participant needs for special assistance on a 24 hour basis. Appended are an outline on national family programs and services, a table comparing family subsidy/support programs in selected states, a fee schedule, a list of special needs purchases, a copy of the "Quality of Life Questionnaire" administered to families, a satisfaction questionnaire, and a summary of previous project issues. (SW)

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FAMILY SUPPORT PROJECT

FINAL REPORT

FOR THE PERIOD OF

JANUARY 1, 1979 THROUGH SEPTEMBER 30, 1979

OCTOBER 31, 1979

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FINAL REPORT
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PURPOSE

The purpose of the Family Support Project is to provide a variety of family support services; case management, family consultation and therapy, respite services, and special needs payments, which are designed to maintain substantially handicapped children of Clinton, Eaton, and Ingham Counties in their own communities and whenever possible, in their own homes. Although every effort was made to help maintain these substantially handicapped children in their own homes, this was not always possible. In such cases, the primary purpose then became the maintenance of these individuals in their own communities.

The target population for this project is comprised of severely mentally impaired (SMI) and severely multiply impaired (SXI) children and their families living in Clinton, Eaton, and Ingham Counties. In addition, the group is limited to those under 26 years of age. The disability groups are further defined in terms of the Michigan Special Education Code. These definitions follow:

Rule 3. Severely mentally impaired means a person identified by an educational planning and placement committee, based upon a comprehensive evaluation by a school psychologist, and other pertinent information, as having all the following behavioral characteristics:

(a) Development at a rate approximately 4 1/2 or more standard deviations below the mean as determined through intellectual assessment.

(b) Lack of development primarily in the cognitive domain.

Rule 14. Severely multiply impaired means a person identified by an educational planning and placement committee, based upon previous medical records, any educational history, evaluation by a neurologist, orthopedic surgeon, opthamologist, audiologist, or equivalent, and other pertinent information as having all the following behavioral characteristics:

(a) Severe multiplicity of handicaps in the physical and cognitive domains.

(b) Inability or expected inability to function within other special education programs which deal with a single handicap.

(c) Development at less than the expected rate of age group in the cognitive, affective, or psychomotor domains.

In nine months of operation the project worked with the families of 93 persons who met the above criteria. In each situation, the entire family was determined to be part of the open case and services were offered to all family members.

Table 1 is used to present selected characteristics of the 93 clients who have participated in the project. To provide some comparison, these same characteristics are presented for those 36 Respite Care clients within the same age range. In addition, the mean ages and number of secondary disabilities were tested for significant differences between them while the proportions of assignments to the remaining characteristics were tested for significant differences.

These tests showed that the groups did not significantly differ on the following characteristics: age, best vision, best hearing, type of convulsive disorder, inappropriate affective behavior, or other debilitating conditions. The proportions did differ significantly at a 99.5% confidence level for the level of retardation, best speech, and type of motor dysfunction. The largest single contributing factors for each of these differences were as follows: the project group had more people who were severely retarded; the project group had more people with no speech; and the project group had fewer people with no motor dysfunction. Finally, the mean number of secondary disabilities for the project group was 1.9 while the mean for the Respite Care group was 1.2. This difference was found to be significant at a 99% level of confidence. In summary, this information indicates that the project group was indeed composed of severely and multiply handicapped individuals and that they exhibited a higher number of more severe handicapping characteristics than the regular Respite Care group.

In order to assist these families to maintain their children in the community

Table 1. Distributions of selected characteristics for 93 Family Support Project (FSP) and 36 Respite Care (RC) clients from the ages of 0 through 25

Age	FSP	RC
0-2	12	5
3-5	16	5
6-8	10	2
9-11	19	6
12-14	15	4
15-17	10	7
18-20	3	5
21-23	5	2
24-25	3	0

Level of Retardation	FSP	RC
Borderline	1	5
Mild	3	7
Moderate	15	15
Severe	51	3
Profound	9	0
Unspecified	14	6

Speech Disorder	FSP	RC
No Disorder	4	10
Some Disorder	32	21
No Speech	39	0
Unknown	18	5

Best Vision	FSP	RC
No Impairment	46	19
Moderate to Severe Impairment	10	8
Legal Blindness	4	0
Unknown	33	9

Best Hearing	FSP	RC
No Impairment	62	22
Moderate to Severe Impairment	2	2
Legal Blindness	1	0
Unknown	[illegible]	12

Convulsive Disorder	FSP	RC
None	47	28
Akinetic - Myoclonic	2	0
Focal Seizure	0	0
Autonomic Seizure	0	0
Major Motor Seizure	5	2
Petit Mal Seizure	9	2
Psychomotor Seizure	2	0
Unspecified	16	1
Mixed/Other	7	2
Unknown	5	1

Motor Dysfunction	FSP	RC
None	26	26
Spastic	12	1
Athetoid	5	1
Ataxia	0	0
Mixed	10	1
Other	3	1
Unknown	37	6

Inappropriate Affective Behavior	FSP	RC
Yes	14	1
No	72	29
Unknown	7	6

Other Debilitating Conditions	FSP	RC
Yes	4	0
No	83	32
Unknown	6	4

No. of Secondary Disabilities	FSP	RC
None	7	11
One	24	11
Two	40	10
Three	17	4
Four	5	0

and to do so with minimal financial and psychological distress, four goals were delineated. They were:

1) Increase the proportion of families who maintain substantially handicapped children in the community and, whenever possible, in their own homes.
2) Increase the types and amounts of services used by the group of families who maintain substantially handicapped children in the community and, whenever possible, in their own homes.
3) Gradually reduce the levels of intervention and assistance to individual families who maintain their substantially handicapped children in the community and, whenever possible, in their own homes.
4) Assess the needs and resources of the community in terms of maintaining substantially handicapped children in the community and, whenever possible, in their own homes with a minimum amount of quality intervention and service.

A discussion of the propriety and degree of attainment of each goal can be found in the analysis section of this report.

HISTORY

National

Within the past three years, at least eight other states have implemented family support programs. The details of each program differ but generally they are designed to prevent or lessen the incidence of institutionalization by providing families services for their child or cash assistance to purchase needed services.[1]

Initially, subsidy programs were developed to assist adoptive parents of hard-to-place children. They were developed in several states to provide adoptive families funds equivalent to those received by foster care providers.

Minnesota was the first state to experiment with a direct cash assistance

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[1] "Family Subsidy Programs Evaluated," New Directions, National Association of State Mental Retardation Program Directors, Inc., July, 1979., p. 2.

program. In 1976, the state legislature appropriated money to subsidize 50 families who agreed to maintain their mentally retarded child at home. This program was extended to biological and adoptive families and allowed up to $250 monthly for children under 18 years of age to cover disability related expenses.[2]

In Florida, a program was established in 1977 to determine if cash subsidies could be an effective means of avoiding or terminating institutionalization. Forty seven families received payments ranging from $30 to $680 monthly to assist in caring for their child at home. The amount of the payment was determined by a contract between the family and the Department of Health and Rehabilitative Services. Some of the services purchased were medical and dental care, room and board, respite care, day care, transportation, homemaker services, special clothing, education and training.

In both states it was reported that subsidy programs appeared to be a feasible means of preventing institutionalization. Project staff report that family units benefited in areas of morale, less financial burden, and reduced family tension.

Other states have developed variations of the programs mentioned. Appendices A and B provide summaries of known programs. In addition, programs are presently being developed in Wisconsin and Illinois.

State

In the state of Michigan, attempts to provide support and assistance to families of severely and profoundly disabled children have been made on a local community level for many years. This was done by groups and agencies such as the Association for Retarded Citizens, school districts, mental health programs and private citizens. State involvement in assisting families has been limited to state facilities for the mentally retarded and traditional community agencies.

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[2]Boswell, Christy. Survey of National Family Programs and Services. Department of Public Welfare. St. Paul, Minnesota. 1978.

Deinstitutionalization attempts have been made by the state for several years but for the most part, services were directed at the identified client as opposed to an entire family. Support to prevent and/or avoid institution placement was minimal and efforts to improve the quality of life for the entire family unit were nonexistent.

The issues of strengthening and supporting the entire family unit and assisting families in caring for their retarded children at home had been verbalized by many people and early in 1978, they were recognized by several state legislators. Presentations by parents of severely impaired children and by the Clinton, Eaton, Ingham Community Mental Health Board, to Senate and House fiscal committees included requests for assistance in supporting families with developmentally disabled children.

As a result of these requests, Public Act 407 of 1978, Section 32(2), allocated $100,000 to the Clinton,Eaton,Ingham Community Mental Health Board to establish a pilot family support project. The project proposal was developed using Michigan Department of Mental Health guidelines for such projects (May, 1978). In addition, numerous meetings were held with parent groups to gather their input into the project development. Final approval for the project was given by the Department of Mental Health in December, 1978, to operate a nine month project.

Local

Historically, services to assist the families of the severely retarded person living in the tri-counties have been limited. Minimal intervention services are available through school systems and Community Mental Health, but the need far exceeds the availability. The Lansing School District employed one social worker to serve 250 trainable and severely retarded children. Community Mental Health, Programs for the Mentally Retarded had one staff member assigned to provide therapy and case management to the families of clients under the age of 26 on a limited basis.

Respite Care services were first offered by Community Mental Health in 1974,

in an attempt to assist families who cared for mentally retarded children in their homes. During the past five years, it has been found that the quantity and types of respite care offered were not sufficient to meet existing needs. Many families were not able to fully utilize respite services because of the severity of impairment of their children.

In addition to the need for extended care, a need for specialized behavior treatment was identified. Referrals requesting such services were received at a rate of 5 per month from local school districts, families and social service agencies. No service was available to assist families who needed consultation on how to work with special behavior problems within their home.

Based on these needs and input from parents of severely multiply impaired children, the Family Support Project began in January, 1979. Staff were hired and two representatives of the parent group were appointed to the Programs for the Mentally Retarded advisory council. A parent task force was also formed to continue working with project staff and program evaluators to develop and expand the concepts and services of the project.

DESIGN

Professional Services

Case Management

Case management is the process through which a client's individual program plan is established, implemented, and monitored. This process includes cooperative planning to determine intended client outcomes and the strategies through which these outcomes will be attained; providing, procuring, and coordinating client services; and collecting, organizing, analyzing and reporting information concerning the status of client progress. For the Family Support Project, one case manager has been used.

Family Therapy

This is a form of group therapy in which the family is the therapeutic unit of

interest. Its objective is to alter the home influences that contribute to the emotional and/or behavioral difficulties experienced by one or more of its members. Various methods may be employed, ranging from such things as behavioral management to psychotherapy. To conduct family therapy for the project, one position was used here as well.

Respite Services

Respite services include various types of short-term care to a disabled person, in or out of the home, which are intended to provide temporary relief for his or her family. Four types of such services were offered through this project. Fees for these services were assessed on a sliding scale.

1) Emergency Respite Care. As implemented in this project, emergency respite care was essentially a specialized form of home-based respite care. In order to provide care on a short notice basis, a home-based worker would be placed on on-call status for a specified period of time.

2) Family Friend Respite Care. This type of respite care was expressly designed for the project as a result of task force input. It is short term care that may be provided either in or out of the home. The distinguishing characteristic of this type of respite care is that the family contracts with the care provider directly and they are then reimbursed by the project.

3) Foster Respite Care. Foster respite care involves short-term relief provided outside the home for a period of up to thirty days. Care providers operate foster homes which are licensed for this purpose and they receive specialized training with each recipient of care before it is provided. They are reimbursed by the project.

4) Home-Based Respite Care. This form of respite care is always provided in the home by a worker employed by the project. They also receive specialized training with each recipient of care before it is provided.

Special Needs Purchases

This component of the project was also previously unavailable. It was designed to assist families purchase specialized equipment, structural modifications, and contractual services that are necessary as a direct result of the exceptional needs possessed by individuals who are severely or multiply impaired. The case manager was responsible to help families determine what types of purchases were needed, as well as, pursue alternative funding sources before project funds were used. When administrative guidelines were met, purchases were approved by the project administrator.

Administration

This project was administered through the Life Consultation and Residential Services components of Programs for the Mentally Retarded, Community Mental Health Board of Clinton, Eaton, and Ingham Counties (PMR). The Life Consultation supervisor was responsible for most of the general project coordination, professional services, and special needs purchases. The Residential Services supervisor was responsible for the respite services through the Respite Care coordinator.

In addition to the day-to-day operations of the project, program staff were expected to meet with the task force and other concerned individuals to help further refine the available services. Time was also spent informing interested parties about the project and its progress.

Evaluation

The role of the Board evaluators in this project has had three aspects; planning, obtaining information, and reporting about the project. In the formative stages of the project, evaluators met with the task force and PMR staff to help clarify the design of the project in order to submit a final proposal for funding. Over the course of the project, the evaluators were responsible to coordinate the collection

of information necessary to describe the project in terms of what was intended and what actually happened. They also helped to make decisions about any design changes that occurred. Finally, they were responsible for co-producing and co-editing the interim and final project reports.

Task Force

The parent task force served in an advisory capacity to project staff. Parents of children eligible for the project volunteered to review proposals, operating procedures and progress of the project. Representatives of the task force also participated in public relations functions in behalf of the project.

IMPLEMENTATION

Professional Services

Case Management

At the end of the fiscal year the project case manager was serving 93 families. Services provided vary from family to family depending upon factors such as individual desire to participate in the project, severity or multiplicity of impairment and individual needs. Generally, the project case manager has been involved in the following types of activities:

1) Developing an outreach program in an effort to contact all eligible families.
2) Working with families to assess their needs and educating them as to how the Family Support Project can assist.
3) Working with groups of parents to develop new services as needed, as well as, maintain effective existing services.
4) Referring families seeking services to the project family therapist and working directly with families who do not specifically request this contact.
5) Meeting with special education teachers, occupational therapists, physical therapists, and other professionals to learn about adaptive equipment, special learning aids, and other resources in order to develop a more comprehensive

perspective on the needs of individual children and their families.

6) Developing a public relations program in conjunction with other Community Mental Health staff to educate the community about the project.

7) Working as a liason between biological and foster families to establish an effective and mutually understood working relationship in parenting the child.

8) Assisting families interested in alternative placements to explore their options within the community.

The case manager's level of involvement with individual families fluctuated from family to family; some requiring intensive work while others were contacted only minimally. A major factor effecting case management services was that only one position was used.

Family Therapy

The normal stresses of family life are often exaggerated in families with severely handicapped children. Intense sibling rivalry and resentment, strain on the marital relationship, and a feeling of being drained by the responsibility of the child's care are all too common phenomena. In an effort to minimize these effects, the Family Support Project provides counseling and therapy to family members to assist them in identifying and meeting their emotional needs. As of the end of the fiscal year, 28 families in the program have actively participated in some form of individual and/or family therapy.

A support group for the siblings of severely handicapped children was offered during the summer to work with feelings children have regarding a SMI or SXI brother or sister.

The family therapist has also served as a consultant to families experiencing behavioral problems in the home. Suggestions regarding environmental modification and methods of response have been made to families in an attempt to limit behaviors

that are very disruptive to family life. In addition to individual families he also consulted with the Lansing Society for Autistic Children.

Staff Activity

Table 2 is used to summarize the basic service activities engaged in on behalf of project families. Time not summarized is related to administrative activities. In general, client services tended to increase over the course of the project. The average amount of client services per family per month was 1.9 hours, within a range of outpatient types of contact. The decreases in staff time in September are most likely due to the loss of a temporary position and increased administrative activities around concluding the first fiscal term of the project.

Respite Services

If only one thing could be said about the Family Support Project to describe what changes have taken place, it would probably have to be that respite services have grown; and they have grown in a number of ways. They have grown in both absolute and relative ways. The number of families using respite each month grew from 15 to 52 over the course of the project, a proportional growth from 27% to 56%. For the project, 78 families or 84% used respite services at least once. This growth is, to a large extent, due to a continual influx of families who used the services for the first time. In fact, 40 families or 51% of the users had never used respite services before this project.

In terms of total hours used, substantial growth was also present, although a seasonal peak during the summer months is suggested. Total hours used ranged from 134.0 hours in February to 4756.5 hours in July with an average of 2719 hours per month for the project. The average number of hours used for all families each

Table 2. Reported Family Support Staff Hours for Various Activities

Activity	February	March	April	May
Client Services	31.00	137.50	136.00	170.25
Diagnostic Interview	2.25	43.50	35.25	33.75
Testing	2.00	4.25	0.00	4.25
Crisis Intervention	0.00	0.00	0.00	1.25
Family Contact	23.00	57.25	50.25	92.75
Case Consultation	1.25	6.50	0.00	8.75
Service to Non-Registered Clients	2.50	26.00	50.50	29.50
Consultation and Education	2.00	11.50	59.75	101.00
Totals	33.00	149.00	195.75	271.25

Activity	June	July	August	Sept	TOTALS
Client Services	169.50	183.50	230.00	126.00	1,183.75
Diagnostic Interview	12.50	23.25	61.00	18.25	229.75
Testing	0.00	0.00	0.00	1.75	12.25
Crisis Intervention	1.75	0.25	2.50	2.00	7.75
Family Contact	113.25	99.25	107.00	56.75	599.50
Case Consultation	2.75	6.00	14.50	31.50	71.25
Service to Non-registered clients	39.25	54.75	45.00	15.75	263.25
Consultation and Education	25.50	61.50	77.25	9.50	348.00
Totals	195.00	245.00	307.25	135.50	1,531.75

month ranged from 12.2 hours in March to 55.6 hours in July. Over the project, the average number of hours used for all open cases each month was 34.1 hours per family per month. For comparison, the average number of hours used for all open cases each month in regular Respite Care was 6.7 hours per family per month. Thus, the Family Support Project group averaged slightly over five times the amount of respite usage per family per month when compared to the regular Respite Care group. This difference is significant at a 99% level of confidence.

When only those families who actually used respite services during each month are considered, the average monthly usage ranged from 40.5 hours in March to 106.3 hours in August. For the project, this subgroup averaged 68.4 hours per family per month.

With respect to the three basic types of respite services available, a dramatic shift took place in terms of the emphasis on Family Friend services. This category accounted for the major growth in respite services and, as a result, the proportion of such services grew from 18% in February to 78% by September. Over the course of the project, Family Friend respite care accounted for 69% of the hours used, foster respite care accounted for 21% and home-based respite care accounted for 10%.

These and other bits of information concerning Family Support and regular Respite Care usage are summarized in Tables 3 and 4. In general, it can be seen from these tables that the project has undergone substantial growth while regular Respite Care has remained essentially stable.

Special Needs Purchases

Special needs purchase funds are expended only when other resources are not available. A family needing equipment, services or structural modification makes a request to the project case manager. The case manager processes the request by determining if other agencies can meet the stated need, reviews the cost and writes

Table 3. Family Support Respite Usage, *1979

	Feb.	Mar.	Apr.	May	June	July	Aug.	Sept.	Totals
No. of Families in Project	56	60	66	75	79	85	89	93	93
No. of Families Using Respite	15	18	26	38	51	52	44	52	78
Percent of Families Using Respite	27%	30%	39%	51%	47%	61%	49%	56%	84%
No. of First Time Respite Users (Ever)	1	1	5	8	10	5	3	7	40
(Project)	15	7	13	8	15	5	6	9	78
Percent of Monthly Users Who Are First Time Users (Ever)	7%	6%	19%	21%	20%	10%	7%	13%	51%
(Project)	100%	39%	50%	21%	29%	10%	14%	17%	100%
Total Hours of Respite Used	761.0	729.0	1682.5	2293.0	3309.5	4756.5	4677.5	3540.25	21749.75
Family Friend	134.0	189.0	787.0	1666.0	2586.5	3632.5	3207.5	2758.75	14961.25
Foster Care	429.5	404.0	634.5	423.5	573.0	810.0	948.0	274.0	4496.5
Home Based	134.5	136.0	261.0	203.5	150.0	314.0	485.5	507.5	2192.0
Average Respite Hours Used By All Families	13.6	12.2	25.5	30.6	41.9	55.6	52.6	38.1	233.9
Average Respite Hours Used By Those Using Respite	50.1	40.5	64.7	60.3	64.9	91.5	106.3	68.1	278.8
Percent of Respite That Was Family Friend	18%	26%	47%	73%	78%	76%	69%	78%	69%
Percent of Respite That Was Foster Care	65%	55%	38%	18%	17%	17%	20%	8%	21%
Percent of Respite That Was Home Based	17%	19%	15%	9%	5%	7%	11%	14%	10%

*Adjusted for late date from Family Friend Users

Table 4. Regular Respite Care Usage, 1979

	Feb.	Mar.	Apr.	May	June	July	Aug.	Sept.	Totals
No. of Families in Respite Care	67	68	67	55	57	59	57	59	59
No. of Families Using Respite	13	14	10	12	7	12	13	15	42
Percent of Families Using Respite	19%	21%	15%	22%	12%	20%	23%	25%	71%
No. of First Time Respite Users	0	2	0	1	0	0	4	0	7
Percent of Monthly Users Who Are First Time Users	0%	14%	0%	8%	0%	0%	31%	0%	17%
Total Hours of Respite Used	260.0	632.0	439.75	282.0	267.0	328.5	627.5	422.25	3259.0
Foster Care	175.0	400.0	347.0	142.5	168.0	158.0	479.0	63.0	1932.5
Home Based	85.0	232.0	92.75	139.5	99.0	170.5	148.5	359.25	1326.5
Average Respite Hours Used By All Families	3.9	9.3	6.6	5.1	4.7	5.6	11.0	7.2	55.2
Average Respite Hours Used By Those Using Respite	20.0	45.1	44.0	23.5	38.1	27.5	48.3	28.2	77.6
Percent of Respite That Was Foster Care	67%	63%	79%	51%	63%	48%	76%	15%	59%
Percent of Respite That Was Home-Based	33%	37%	21%	49%	37%	52%	24%	85%	41%

a justification for expenditure of funds. The request is then sent to a project administrator for determination. Approved requests are processed by the finance office of the Community Mental Health Board using standard purchasing procedures. Families are asked to pay for a portion of the purchase based upon their ability to pay. See Appendix C for the fee schedule.

During the nine months of project operation, approximately $8,500 was spent for equipment and service purchases. Such equipment as positioning devices, bath chairs, and special orthopedic shoes were bought. Services included specialized child care assistance from Visiting Nurses Association to care for a child whose mother broke her ankle and ambulance transportation for a multiply impaired child who had to be moved from a hospital. Physical therapy was also provided to several youngsters during the local teachers strike. A listing of purchases can be found in Appendix D.

Need for approximately $3,000 worth of equipment was referred to other sources by the project case manager. Purchases were made by insurance carriers and Michigan Crippled Children's Society. Intermediate school districts were also asked to provide service to some children and responded favorably.

Administration

The Family Support Project was administered jointly by staff from the Life Consultation and Residential Services components of Programs for the Mentally Retarded of the Clinton, Eaton, and Ingham Community Mental Health Board. Life Consultation was responsible for providing case management and family therapy services while the Residential component provided respite care. Supervisors of each component have been administratively responsible for project operations, however only the Residential Services supervisor was financially charged to the project during the fiscal year 1978-79.

While decisions in the project are ultimately a PMR administrative responsibility, the decision making process is frequently a joint activity between project

staff and families. The Family Support Project task force and staff met on a regular basis to discuss the implementation of the project and related issues. This was an opportunity to get participant reactions, feedback, and needs brought regularly to the attention of project staff.

The Family Support Project endeavored to establish equitable, reasonable policy guidelines while, at the same time, remaining flexible enough to be responsive to clients needs. As issues arose needing clarification and direction, they were discussed at weekly project staff meetings, discussed with parents at task force meetings and policy written. Issues which have been handled in this manner, have included guidelines for special needs payment approval, definition of services available for foster families, as well as definitions of appropriate levels and usages of respite care.

Finally, of administrative concern, is the project budget. Table 5 summarizes the budget status as of the end of the fiscal year. Further discussion of expenditures, unexpended funds and other financial considerations can be found in the analysis section of this report.

Evaluation

As previously discussed, the Community Mental Health Board evaluation unit has participated in planning the design of the project, obtaining relevant information, and reporting about the project. In terms of planning, the unit became involved during the early stages of the project. The final proposal is the product of several revisions and refinements of the original concepts. The primary focus for reporting has been to produce two interim and one final report in conjunction with the project staff. The unit has also helped provide answers to specific requests for information from the Department of Mental Health and other interested audiences.

The remainder of this section will summarize information that has been collected in relation to the four project goals. Some information relevant to these goals has

Table 5. Family Support Project Budget Status, January 1 through September 30, 1979

Description	Budget	Expended	Balance
Salary	37,042.00	40,770.21	(3,728.21)
Fringe Berefits	8,173.00	7,078.21	1,094.79
Supplies	561.00	650.43	(89.43)
Respite Care	29,753.00	19,205.98	10,547.02
Equipment	21,270.00	7,679.41	13,590.59
Contract Services	8,466.00	1,571.58	6,894.42
Telephone	2,012.00	902.50	1,109.50
Travel	1,658.00	2,077.36	(419.36)
Insurance	0.00	146.02	(146.02)
Rent	2,177.00	2,176.91	0.09
Dues	0.00	38.40	(38.40)
Total	111,112.00	82,297.01	28,814.99

been covered in other sections will not be reported here, however.

Goal 1: Increase the proportion of families who maintain substantially handicapped children in the community and, whenever possible, in their own homes.

The intended activities related to this goal were to identify the number of families in Clinton, Eaton, and Ingham counties with substantially handicapped children living at home, alternative living facilities in the community, or at Hillcrest Regional Center for Developmental Disabilities; and to assess the extent to which these children lived where they did.

An estimate of the number of residents of Clinton, Eaton, and Ingham counties who would be eligible for the project on the basis of their compliance with the admission criteria, 230, is presented in Table 6. Although this number is the result of much outreach activity, it should probably still be considered to be a slight underestimate. The number of people living in the community but not in the project should be considered a conservative estimate because it does not include preschool children or school age children not attending one of the two major schools intended to serve eligible children. The Hillcrest count is conservative since it does not include eligible people who are residents of other state mental retardation institutions.

Efforts to outreach families with children residing in state institutions were hindered by confidentiality and release of information regulations. Project staff could not obtain the necessary permission to adequately assess the placement and service needs of this group.

Tables 7, 8, and 9 show three ways to represent the extent to which project participants lived where they did. Tables 7 and 8 indicate that there was virtually no residential movement over the course of the project. The movement that did occur was not significant. A slight tendency for children to move from natural homes to foster homes is suggested through Table 9, however.

Goal 2: Increase the types and amounts of services used by the group of families

Table 6. Severely mentally impaired (SMI) or severely multiply impaired (SXI) residents of Clinton, Eaton, and Ingham counties from the ages of zero through 25 identified as of September 30, 1979

In the Project:	93
Not in the Project and Living in the Community:	74*
Not in the Project and Living in Hillcrest:	63+
Total:	230#

*The number of children and adults enrolled in SMI, SXI, or autistic programs at the Beekman Center or Ingham Developmental Center minus the number of project children in those programs only. Consequently, this should be thought of as a conservative estimate.

+The number of children and adults considered by the Hillcrest staff to be eligible for the project. Since this number does not include tri-county residents living in other institutions, this should also be considered a conservative estimate.

#A conservative estimate for the above reasons.

Table 7. Type of living situation for participants at the beginning and end of the project

Living Situation	January, 1979		September, 1979	
	No.	%	No.	%
Community	93	100%	92	99%
Natural Home	71	76%	66	71%
Foster Home	20	22%	25	27%
Other Community Home	2	2%	1	1%
Hillcrest	0	0%	1	1%

Table 8. Average length of stay for project participants in various types of homes by type of home at the end of the project

		AVERAGE MONTHS OF STAY			
Residence as of September 30	No.	Natural Home	Foster Home	Other Comm. Home	Hillcrest
Natural Home	66	9	0	0	0
Foster Home (Mean)	25	0.84	7.84	0.28	0.04
(Median)		0	9	0	0
Other Community Home	1	0	0	9	0
Hillcrest	1	4	0	3	2

Table 9. Patterns of residential movement during the project

Movement	Number
Always at Natural Home	66
Always at Foster Home	20
Always at Other Community Home	1
From Natural Home to Foster Home	4
From Natural Home to Other Community Home to Hillcrest	1
From Other Community Home to Hillcrest to Foster Home	1

who maintain substantially handicapped children in the community and, whenever possible, in their own homes.

The basic activities related to this goal were to identify the types of services available to families and to assess their usage. Due to an inadvertent omission of items related to usage of non-project services on the final questionnaire, a quantitative description of such usage was not collected. However, a summary of the basic types of services from other agencies was collected through administrative logs. The usage of project services in terms of staff hours and respite services will also be briefly discussed here.

The agencies to be discussed next have provided various types of services to project participants, although it should be remembered that no estimates of the amounts of usage are being made. Be that as it may, it is probably reasonable to assume that the most highly used services by this group are those of the local schools. Virtually all of the project children attended some type of program. The Easter Seal Society has provided families with adaptive equipment and sponsored a family camping weekend. The Michigan Crippled Children's Society has also provided adaptive equipment, as well as the purchase of physical therapy services. Physical therapy was also provided by that unit of Sparrow Hospital. Nursing, nutrition and other health-related services were available through visiting nurses services, county health departments and Lansing General, Sparrow, or St. Lawrence Hospitals. Genetic counseling was offered through the Michigan State University Genetics Clinic. Family counseling along with occasional assistance in foster home placements could be obtained through Catholic Social Services or Family and Child Services. Hillcrest occasionally provided homes for community foster respite care or assessments for possible inpatient admissions. Finally, the Department of Social Services local offices provided financial assistance and protective services.

Before the inception of this project, virtually no services beyond respite

services were offered to Respite Care clients of school age. This is primarily because no full-time staff were directly available to do so. During the course of the project, however, the Family Support Group averaged 1.93 hours of staff service per family per month for all cases open each month. This time includes the activities of diagnostic interviews, testing, crisis intervention, family contact, case consultation, and service to non-registered clients. The regular Respite Care group averaged 0.34 hours of staff service per family per month for comparable activities. This difference in average usage hours is also significant at a 99% level of confidence.

During the previous year, 1978, the 93 project families averaged 7.6 hours of respite service per family per month. This average takes into account even those families who were not agency clients at the time. During the project, these same families averaged 29.2 hours per family per month, a significant difference at a 99% confidence level. When considering only open cases on a month by month basis, the Family Support group averaged 34.1 hours per family per month during the project, while the Respite Care group averaged 6.7 hours per family per month, also a significant difference with 99% confidence.

Goal 3: Gradually reduce the levels of intervention and assistance to individual families who maintain their substantially handicapped children in the community and, whenever possible, in their own homes.

The activities for this goal were essentially the same as those for the previous goal, but with an individual emphasis. However, due to a number of factors, such as, the short length of time many families have used service, the confounding influences of an expanding project, possible cyclic trends in service usage, and the limitations of the current data processing systems regarding the analysis of individual data over time, no statistics were performed related to this goal. As more time passes, a variety of time series analysis models will be piloted to judge their sensitivity to the question of interest, does the level of intervention and assistance decline over time?

For now, a subjective analysis of staff activity contact with individual families and respite usage indicate no trend toward declining contacts. Also, since it cannot be shown otherwise, it is assumed that the trend toward increased staff activity and respite service hours for the project group as a whole is a result of a trend in increases by individual families over time.

Goal 4: Assess the needs and resources of the community in terms of maintaining substantially handicapped children in the community and, whenever possible, in their own homes with a minimum amount of quality intervention and service.

All activities of the project have, to varying degrees, contributed to the development of a needs and resources assessment. These activities together were intended to address six subgoals: identify the eligible population; identify the major factors that tend to institutionalize these people; identify the factors that tend to keep them in the community and, particularly, at home; identify the types and amounts of services available to the population families; identify additional services that appear to be needed; and recommend further action to be taken based on what has been learned.

An estimate of the size of the eligible population, 230 people, has been discussed under Goal 1 and summarized in Table 6. Since this estimate only counts identified individuals, and it is likely that other people within the arbitrary age limits could be identified, it is reasonable to consider this to be at least a slightly conservative estimate. If the age limit were lifted, this estimate would become very conservative.

In terms of the factors that tend to contribute to institutionalization or to keeping people at home, a number of people felt that these factors could be related to a somewhat amorphous concept that has been labeled, quality of life for the family as a whole. Some of the factors that project staff felt were involved in many of the requests for assistance in institutionalizing different individuals

over the years were such things as severity of medical problems, severity of behavioral problems, availability of relevant interventions in the community, stress on siblings, and the duration of such problems.

In an attempt to determine if parents differed in their perceptions of their own quality of life, a survey instrument, Appendix E, was administered to three groups of parents; those in the project, those with eligible children in school but not in the project, and those with eligible children in Hillcrest. However, response rates of less than 15% preclude any definitive statements regarding their responses. Because of this, only some general information is summarized in Table 10. Very quickly, the groups showed very few differences in their responses. They showed no differences in their ratings of overall quality of life, good to very good; the total score response to the importance of all factors, important to very important; or the total score response to how well their needs for all factors were being met, moderately well to well.

The groups did significantly differ on four items with 95% confidence. For material comforts, all groups rated this important to very important, but the project group rated them less so. For helping and encouraging others, the community groups rated this moderately important to important, the project group less so; and the Hillcrest group rated this important to very important. In terms of needs being met for helping and encouraging others, the non-project community group's rating was slightly well to moderately well met; the project group's rating was moderately well to well met; and the Hillcrest group's rating was, well to very well met. For work, the non-project community group rated this moderately important to important. while the other two rated it important to very important.

Although the groups did not differ in their responses to each of the having and raising children items, they will also be presented. All groups considered having and raising handicapped or non-handicapped children important to very important. However, they saw their needs in terms of non-handicapped children were being

Table 10. Quality of Life Questionnaire Summary

Responses are for project (P), non-project community (NPC), and Hillcrest (H) groups combined, except when group responses differed significantly at a 95% level of confidence.

A. Material comforts: (P) - important to very important; NPC - important to very important; H - important to very important. Needs being met moderately well to well.

B. Health and personal safety: Important to very important and needs being met moderately well to well.

C. Relationships with your parents, brothers, sisters and other relatives: Important to very important and needs being met well to very well.

D. Having and raising children: Important to very important and needs being met well to very well.

D1. Having and raising handicapped children: Important to very important and needs being met moderately well to well.

D2. Having and raising non-handicapped children: Important to very important and needs being met well to very well.

E. Close relationship with a husband/wife: Important to very important and needs being met well to very well.

F. Close friends: Important to very important and needs being met well to very well.

G. Helping and encouraging others: (P) - Moderately important to important; (NPC) - moderately important to important; (H) - important to very important. Needs being met (P) - moderately well to well; (NPC) only slightly well to moderately well; (H) - well to very well.

H. Participation in activities related to local and national government and public affairs: Only slightly important to moderately important and needs being met moderately well.

I. Learning: Important to very important and needs being met moderately well to well.

J. Understanding yourself: Important to very important and needs being met moderately well to well.

K. Work: (P) - Important to very important; (NPC) - moderately important to important; (H) - important to very important. Needs being met moderately well to well.

L. Expressing yourself: Moderately important to important and needs being met moderately well to well.

Table 10. (continued)

M. Socializing: Moderately important to important and needs being met moderately well to well.

N. Reading, listening to music or observing: Important to very important and needs being met well.

O. Participation in active recreation: Moderately important to important and needs being met moderately well to well.

Overall Quality of Life: Good to very good.

Total score response to the importance of all factors: important to very important.

Total score response to how well needs for all factors were being met: Moderately well to well.

well to very well met while their needs in terms of handicapped children were being moderately well to well met.

The basic types of non-project services used by the families have been discussed under Goal 2. Unfortunately, information concerning the extent of usage was not collected. The types and amounts of project services used by the families are primarily discussed under professional services, respite services, and special needs purchases. In terms of professional services, a case management load of 93 is extremely large by any standards and, thus, the provision of services to individual families was hampered. For family therapy, it would have been possible to serve more than the 28 families with the available resources, because this service was relatively slow to develop clientelle. Since the budgets for both respite services and special needs purchases were not fully expended, it also would have been possible to provide additional services in these areas.

Input to staff regarding additional services that appeared to be needed was provided through consultation with families directly and by way of the task force, as well as, through the two questionnaires. Three basic need areas that were amplified by the conversations were: parent-to-parent support as early as possible after the discovery that a child possesses severely handicapping characteristics; specialized training opportunities for family and staff who care for such children; and additional short and long term community residential alternatives for individuals with highly specialized needs due to exceptional medically related or behaviorally related problems.

Additional input regarding improvement of existing services or inclusion of additional services was solicited from both project and regular Respite Care families through a satisfaction questionnaire in Appendix E. Again, response rates around 20% preclude definitive interpretations and, thus, only brief summaries of the responses are presented in Tables 11 and 12.

Except for the services used, the responses by both groups are quite similar.

Table 11.Family Support group responses to satisfaction questionaire. (35 returns, 20% response rate)

1. Check the services you have used and indicate your overall degree of satisfaction with them.

Service	# Reporting		% Responding				
	Yes	No	# Resp.	Very Satis.	Satis.	Neutral	Dissat.	Very Dissat.
Case Management	11	11	15	73	13	7	7	0
Counseling/Therapy	1	15	1	100	0	0	0	0
Emergency Respite Care	2	16	3	67	0	33	0	0
Family Friend Respite Care	21	6	21	81	10	10	0	0
Foster Respite Care	6	6	17	71	12	6	0	12
Home-Based Respite Care	7	13	7	57	43	0	0	0
Special Needs Purchases	7	13	8	75	13	0	0	13
All Services Used	-	-	4	50	50	0	0	0

II. How would you improve

	% Responding					
	No Resp.	Don't Know	State-ment of Satis.	State-ment of Dissat.	No improve-ment Needed	Specific Recomm-endations
Case Management	91	0	3	3	0	3
Counseling/Therapy	94	0	0	3	0	3
Emergency Respite Care	91	0	3	3	0	3
Family Friend Respite Care	66	3	17	3	3	9
Foster Respite Care	77	3	6	0	0	14
Home-Based Respite Care	86	3	0	0	0	11
Special Needs Purchases	89	0	6	0	0	6
III. Services Needed	77	0	0	0	14	9
IV. Other Comments	80	0	17	0	0	3

II., III., & IV. Paraphrased Recommendations (N=21)

Case Management: Clarify its role.
Counseling/Therapy: Clarify its role
Emergency Respite Care: Clarify its role.
Family Friend Respite Care: Make family members over 18 eligible to be reimbursed. Raise the daily repayment limit. Have family friends attend training sessions and report on care episodes.
Foster Respite Care: Have more care providers in the suburbs. Have more care providers closer to schools. Insure the quality of families. Have more responsible, clean care providers. Have foster care providers attend training sessions and report on care episodes.
ome Based Respite Care: Have more workers. Introduce families to more workers. Raise the salaries of workers. Offer more training to workers.
Special Needs Purchase: Consider the needs of the entire family for special purchases.

Table 11. (continued)

III. Services Needed: Offer more care providers near a family's home. Provide drivers for children's daytime appointments. Provide respite services to cover parents' work time.

IV. Other Comments: Provide a cash grant rather than special needs purchases.

Table 12. Respite Care group responses to satisfaction questionnaire (22 returns, 19% response rate).

I. Check the services you have used and indicate your overall degree of satisfaction with them.

	# Reporting		% Responding				
Service	Yes	No	# Resp.	Very Satis.	Satis	Neutral	Dissat.	Very Dissatified
Case Management	3	9	3	100	0	0	0	0
Counseling/Therapy	2	9	2	50	50	0	0	0
Emergency Respite Care	1	9	1	100	0	0	0	0
Family Friend Respite Care	0	9	0	0	0	0	0	0
Foster Respite Care	2	6	2	50	0	50	0	0
Home Based Respite Care	16	5	17	94	6	0	0	0
Special Needs Purchases	0	8	0	0	0	0	0	0
All Services Used	0	9	1	100	0	0	0	0

II. How would you improve?

	% Responding					
Service	No Resp.	Don't Know	State-ment of Satis.	State-ment of Dissat.	No Improve-ment Needed	Specific Recommen-dations
Case Management	95	0	5	0	0	0
Counseling/Therapy	95	0	5	0	0	0
Emergency Respite Care	91	0	5	0	0	0
Family Friend Respite Care	95	0	0	0	0	5
Foster Respite Care	95	0	5	0	0	0
Home Based Respite Care	32	5	36	0	14	14
Special Needs Purchases	91	9	0	0	0	0
III. Services Needed	64	5	5	5	14	9
IV. Other Comments	86	0	9	5	0	0

II., III., & IV. Paraphrased Recommendations (N=7)

Emergency Respite Care: Clarify the procedures.
Family Friend Respite Care: Offer more of this service.
Home Based Respite Care: Offer more workers. Inform more families of this service. Don't place children with others who are also handicapped.
III. Services Needed: Offer weekend respite care for adults. Offer assistance in planning for a child's future needs.

For the most part, both groups were generally satisfied with the services they had used. When asked for suggestions to improve services, very few people offered specific recommendations. Those suggestions that were offered were quite similar to those previously discussed. Since there was a relatively low number, all specific suggestions have been paraphrased in the tables.

The sixth sub-goal, development of recommendations, is summarized in the final section of this report. They represent an attempt to continue what was useful, modify those things that appeared to need improvement, and add workable components that would strengthen the currently available service delivery system.

ANALYSIS

Unresolved Issues

The Family Support Project, being a pilot project, has been faced with a number of issues relating to the organization and operation of services being provided. These are an outgrowth of operationalizing the concepts set forth in the project proposal and attempting to provide services that meet the needs of project participants. Some of the issues have been raised by staff, while others have come from parents and participants in the project. Resolution of these questions is approached with an attempt to be responsive to client needs and, at the same time, to develop sound programmatic and fiscal policy.

The two interim project reports listed fourteen separate issues that had been addressed by project staff. All but two of these were resolved during the course of the project and became part of the project's operating procedures.

The two unresolved issues are: 1) "What is the most appropriate mechanism for handling Family Support Project emergencies?" and 2) "How many staff people need to be employed by the project?"

The first issue needs to be attended to because the existing Community Mental Health emergency service focuses on responding to the affective needs of clients.

Emergencies involving Family Support clients often require coordinating respite services and knowledge of facilities for placement. Community Mental Health is in the process of developing policy and reimbursement schedules in order to implement a program level emergency service. It is anticipated that this will take effect early in fiscal year 1979-80 and will provide a 24 hour emergency system for Family Support Project participants.

The second issue is one which will require continued analysis. Several variables must be considered in determining the optimal staffing of such a project. Two professional and one para-professional staff were assigned to the project initially. This staffing pattern is less than originally proposed by Community Mental Health and below the standards set by the Michigan Department of Mental Health, but beyond what the parent task force viewed as desirable. The task force felt that minimal funds should be expended for staff in order that a greater amount could be allocated to respite services and special needs purchases.

Although further assessment is necessary, the following statements can be made about the present staffing pattern.

1) The case manager has too large a case load to be able to maintain regular contact with all project participants.

2) The respite care aide position has taken on some clerical duties because clerical assistance to the project is limited.

3) The therapist position does not adhere to traditional therapeutic models and methods must be developed to expand this role.

In addition to these previous issues, during the final quarter requests for services and information provided by the family task force created three other unresolved issues. The first concerns population definition. Requests for inclusion into the project have been made by families with severely multiply impaired and severely mentally impaired people over the age of 26. Requests for service have also been made in behalf of children with mild yet multiple handicaps. Inclusion

of these groups would necessitate a change in the defined population.

The second issue was suggested by several families. These families make frequent use of respite services and would like to see more consistent staffing of this service. Parents feel that if home based respite workers were paid more and could work more hours, their services would be retained for a longer period of time. They also feel that if foster providers were paid at a rate equivalent to that paid by state institutions that higher quality and more providers could be attracted to the program. This issue must be assessed in more detail, taking into consideration fiscal and personnel factors.

The final issue is related to billing and payment for respite services. Families are being billed by the agency for co-payment on a sliding fee schedule and at the same time are being sent checks by the agency. This dual system tends to be confusing and appears to be inefficient. Assessment of billing and pay-back procedures should be undertaken.

Unintended Outcomes

The Family Support Project, being a pilot project, was an untested exercise in how to provide services to the families of severely impaired children. In attempting to provide such services, there were many outcomes that were not anticipated at the time the project was written. Many of these unintended outcomes have been amplified in previous reports as unresolved issues and are listed for reference in Appendix G.

In the nine months of operation the major unintended outcomes were a restructuring of project goals, underexpenditure of funds, an increased awareness of abuse and neglect, a change in respite care services, a recognition of evaluation needs, and interest in the project on a state and national level. Project goals were modified within the first months of operation to include children living in foster homes because it became evident that living in the community, whether or not with

one's family, was more beneficial than living in an institution. The family unit sometimes could be strengthened if alternative care could be arranged in the individual's local community.

It was not the intention of the project to lapse funds during its three quarters of operation. Underexpenditure is not an indication that the project is not highly needed. Rather, it is an outgrowth of longer than anticipated start-up times and artificially imposed budgetary constraints to guard against over extension of the project. There was no past experience with this project, so estimates of utilization were relatively crude. Staff were aware of this fact, and hence employed relatively conservative fiscal restraint to maintain the financial integrity of the project.

Prior to this project, Community Mental Health had little experience in serving severely impaired children. In serving this high risk population, came the need to become more aware of situations that could appear abusive or neglectful. Staff had to review existing laws and regulations regarding abuse and establish a working relation with the Children's Protective Services Division of the Department of Social Services.

A third unintended outcome was the dramatic shift in the usage pattern of respite care services that came about with the addition of family friend respite care. This service has become the most popular and the most utilized type of respite service.

The evaluation plan proposed with the project was thorough, but several factors did not allow for a complete implementation of the plan. Funding was not budgeted for evaluation services and therefore was left to existing staff. Project staff had little experience in evaluation and Community Mental Health evaluation staff had limited time to devote to the project. Although evaluation of the project meets minimum expectations, much more could have been done.

Finally, interest in the project around the state and nation was not anticipated. Numerous service systems and decision makers around Michigan have expressed an interest in the Family Support Project. Nationally, requests for information about the project have come from several states who are contemplating similar programs.

From these outcomes, even though they were not intended, project staff have learned a great deal that could be of assistance in revising and expanding the concept of Family Support Programs.

Goals

Goal 1: Increase the proportion of families who maintain substantially handicapped children in the community and, whenever possible, in their own homes.

Attainment. Information related to this goal provided in the implementation section demonstrates that the proportion of families who maintained their children at home or in the community changed very little, and that those changes which did occur were not significant. It is therefore, concluded that the first project goal has not yet been attained.

Propriety. Consideration of the nature of this goal shows that in order for it to be attained, significant movement of individuals from the institutions back into the community and/or a reduction in the rate of new institutionalizations must take place. The former process can conceivably take place in a relatively short period of time, while the latter would probably take longer to show an effect. Because the initial emphasis of this project has been on improving the quality of life of those people already in the community, it was totally expected that this goal would not be attained during the first funding period. Future activities by project staff with families of institution residents along with all other community placement efforts of the agency should have a positive effect on this goal. As a result, the first goal is considered to be a proper one for the project, but the time needed for changes at this level to develop is considered to be longer than nine months.

Goal 2: Increase the types and amounts of services used by the group of families who maintain substantially handicapped children in the community and, whenever possible, in their own homes.

Attainment. As a result of the project, eligible families have received a number of support services not previously available to them. Some services, such as, family friend respite care and special needs purchases, were never before available to any agency clients. The average amounts of staff services and respite services used by the group were significantly larger than they had previously used, as well as, significantly larger than what was used by the regular Respite Care comparison group over the same period of time. Thus, it is concluded that the second project goal was attained.

Propriety. The underlying assumptions of this goal are that the types and amounts of services previously available to this group were inadequate to meet their needs and, as a result, many children were unnecessarily institutionalized or forced to leave their families for an alternative community living situation. It is further assumed that providing a higher volume of more diversified services will alleviate this situation, thus, creating an impact on Goal 1. Based on the high number of people currently residing in institutions, the energetic requests by families for various types of assistance, and the significant increases in the actual usage of services, the first assumption appears to be quite reasonable. The second assumption seems reasonable to the extent that the services provided actually meet the real needs of the families in question. Over time, movement toward Goal 1 should be a good indicator of how well these needs are being met.

As long as the group of families have not had their needs properly met in terms of the types and amounts of available services, the second goal remains proper. However, as the service system grows, a condition should eventually be reached where a relatively constant amount of services can meet the changing needs of individual families. As this condition is approached, the focus of this goal

would more properly become to maintain the types and amounts of services used by these families. Unfortunately, this condition is not expected to be reached soon.

Goal 3: Gradually reduce the levels of intervention and assistance to individual families who maintain their substantially handicapped children in the community and, whenever possible, in their own homes.

Attainment. Several factors discussed in the implementation section have precluded making a definite statement regarding the attainment of Goal 3 at this time. Nevertheless, the best available estimates suggest that this goal was not attained over the course of the project.

Propriety. Upon initial review, many people have considered this goal to be directly contradictory to the second goal. However, the subtle distinction between individual and group usage makes it possible to attain both goals at the same time. In general terms, the desired pattern of usage would be that individual families would initially show an increase in service utilization over some period of time; but, as they have some needs met through one time expenditures and develop their own skills to address problems and engage the generic service systems, a gradual decline in overall utilization will result, probably leveling off at some point. Over a period of time, the service utilization of some families would be on the rise while others would be on the decline. Under conditions where the service delivery system is initially inadequate to meet all families' needs and then the overall level of intervention is increased to meet these individual needs, the group usage patterns should show an initial increase until individual increases and decreases begin to cancel each other out. At such a time, the group usage pattern would become relatively constant. Unfortunately, a similar group usage pattern would result if the increased quantity of services were not sufficient to meet all individual needs. In this case, the limited available resources would

determine the overall group usage. The task then becomes to determine the reasons for the stabilized group patterns when they occur. Addressing the extent to which this goal is met may help to provide an answer.

In terms of the three basic categories of project services, professional services, respite services, and special needs purchases, a possible pattern of usage for many families may go something like this. Special needs purchases will be relatively high initially and then taper off to virtually nothing. Professional support services will correspond to the degree and amount of special problems that need to be resolved, which could tend to be more likely during earlier contacts. Finally, respite services will initially rise to some continuing pattern of usage which will show some cycles over time. The complexities of measuring and analyzing such activities do not make this a simple task, but future efforts may show any trends that develop.

Goal 4: Assess the needs and resources of the community in terms of maintaining substantially handicapped children in the community and, whenever possible, in their own homes,with a minimum amount of quality intervention and service.

Attainment. Of the four goals, this is perhaps the most difficult one on which to make a determination of attainment. This is so because the concepts of needs and resources, by design, will take on different meanings from family to family. As a result, the composite needs and resources become very difficult to describe. The six subgoals discussed in the implementation section represent an attempt to identify some major steps in this needs and resources assessment. To varying degrees, all of the six subgoals have been addressed and new information has been generated. However, as is always the case with goals such as this, more could have been done. Consequently, Goal 4 is considered to be partially attained.

Propriety. In terms of the overall value of the project, this goal represents the attempt to synthesize all that has been done and all that yet needs to be done

in this community in order to adequately meet the needs of a very special segment of it. To the extent that other communities possess comparable needs, this effort may be beneficial to them as well. For these reasons, this goal should continue to be pursued as part of a conscientious, self-correcting process to develop a responsive service delivery system.

RECOMMENDATIONS

As a result of nine months of operational experience with documentation, and in consultation with parents, consumers, and professionals, the following recommendations have been made concerning the Family Support Project:

1) That a proposal be submitted to the Michigan Department of Mental Health for the continuation and expansion of this project. That such a proposal will request fiscal support for project continuation with additional funding as needed to implement the following recommendations.
2) The arbitrary limits in the use of respite services be removed to better assess the effect of respite services being provided in full response to participant needs.
3) An official emergency respite service system be established as part of an agency wide on-call system in response to participant needs for special assistance on a 24 hour basis.
4) Additional case management and clerical staff be added to meet increased participant numbers and to provide appropriate client/staff ratios.
5) That administrative reorganization occur to clearly define supervisory responsibility into a single service unit.
6) That the concept of a family subsidy be operationalized. This subsidy would be based upon individual family need with specifically defined program plans. The family subsidy would be monitored by the families' case manager.

7) That the Family Support Project include families with children residing at state institutions with a goal of assisting these families as they return their children to the community.

8) That a Parent to Parent support group be initiated similar to the Pilot Parent Program developed by the Canadian Association for Retarded Citizens.

9) That training, education, and information sessions be conducted for biological and foster families on a regular basis.

10) That additional and more systematic training be offered to Family Friend and Home-Based respite care providers to better prepare them to care for severely involved participants.

11) That consideration be given to the development of residential alternatives for the population served by the project. Special attention should be given to housing for the autistic, medically impaired, and behavioral problem child who needs specialized services such as evaluation, diagnosis and treatment.

12) That an evaluation of reimbursement to care providers be undertaken with consideration to increasing pay to foster care and home based workers in order to bring them to parity with Michigan Department of Mental Health providers.

Appendix A. National Family Programs and Services
(C. Boswell, Fall, 1978)

1. Oklahoma - Medical Payments Adoption Subsidy

-Created by 1977 Legislation.
-For adoptive parents of hard-to-place children.
-Provides economic incentives to adoptive parents.
-Payments include all remedial medical expenses not covered by the adoptive parents' insurance incurred with any physical or mental condition existing prior to the adoption.
-Services cease when child reaches 18 years old.

2. Montana - Adoption Subsidy

-1977 Legislation
-For adoptive parents of hard-to-place children.
-Adoptive families may receive a subsidy in the form of services only or financially. The subsidy may not exceed the sum allowable under foster care.

3. Rhode Island - Parent Deinstitutionalization Subsidy Aid Program

-1977 Legislature
-Provides for financial assistance to natural, foster, or adoptive programs to care for a retarded person who is under legal authority of the state and is confined to a state institution.
-For retarded children and adults.
-Foster parents must be licensed.
-All applicant families must participate in in-service training sessions to be eligible. The in-service is part of a home training program to train applicants in mental retardation and specialized training techniques. Sessions are ongoing.
-Payments range from $160 - $300/month based on degree of disability.
-Payment schedule based on disability level:

1. Severely/Profcundly MR

$60/wk. for basic care $15/wk. for training	natural/adoptive
$55/wk. for basic care $15/wk. for training	foster

2. Moderately MR

$45/wk. for basic care $10/wk. for training	natural/adoptive
$40/wk. for basic care $10/wk. for training	foster

3. Mildly MR

$35/wk. for basic care $ 5/wk. for training	natural/adoptive
$30/wk. for basic care $ 5/wk. for training	foster

-Parents must keep monthly records of progress and record all recreational and community activities.
-Program plans are updated every six months with quarterly progress reports.

4. Virginia - Training for Deinstitutionalization

-One year project.
-Provides training for families of formerly institutionalized retarded members (adults and children).

1. Training in developmental skills.
2. For parents who have recently experienced the return or anticipate the return of a family member from a state MR facility.
3. Training in behavior management, parent effectiveness, community resources, first aid, empathy training.

-Project also directed toward community respite care to provide skilled behavioral training for DD persons.

5. Massachusetts - Specialized Home Care Program

-Similar to foster care, but more flexible.
-For MR children and adults.
-Payments include special teaching programs, psychological counseling, physical therapy.
-Provides ongoing training for providers in behavior modification and normalization.

6. Hennepin County, Minnesota

-Federal grant to help families avoid the need for child placement.
-Families receive intensive counseling, referral and advocacy services and assistance in day care and homemaker and volunteer services.

7. Pennsylvania - Family Resource Services Program

-Following information from 1975:
-Two purposes:

1. For families: to provide adequate resources within community to enable family with an MR member to maintain that person at home with minimal stress to the family unit.

   -natural, adoptive foster families or siblings; legal guardian.

2. For retarded individual; to provide adequate resources within the community to enable the individual to remain in a family context in a community setting.

   -Services can apply to retarded persons maintaining their own home or apartment; those living in foster homes, licensed residences, or state hospitals (with limitations). Services can also be provided to married persons who are retarded.

-Resource services available:

1. Respite care.

2. Family Aid: "sitters" for family to go shopping, business meetings, and social events. Family aids must have participated in a training program, be approved by the county, and receive follow-up training.

3. Homemaker Services: household duties for family or provide training in home management for the family, guardian, or retarded person.

4. Transportation: to regular day programs, recreational activities, medical services. Transportation services include taxi, car pools, public, or vans.

5. In-home Therapy: visiting nurses, PT/OT, speech therapy/ audiology/language, visual/mobility therapy, vocational therapy, recreational therapy, dental hygienics, behavioral programming.

6. Family Education/Training: family dynamics, behavior management, parent-child relationships, genetic counseling and family planning.

7. Recreation/Leisure Time Activities.

8. Funding is available for special innovative services.

8. Minnesota - MR - Family Subsidy Program

-1975 Legislation.
-Provide a subsidy to 50 families to care for their retarded child(ren) in the natural or adoptive home
-Maximum payment per family is $250/month

-No income eligibility for family.
-Children must be under age 18 years, have a MR diagnosis, and be eligible for placement in a state institution or licensed community residential facility.
-Grants to families include the costs of:

1. Diagnostic assessments, medical expenses, medications.
2. Special diets and special clothing.
3. Special equipment ranging from medical devices to recreational equipment.
4. Parental relief and child care costs.
5. Educational and training programs (visiting nurses, therapists, behavior management specialists).
6. Preschool program costs.
7. Related transportation costs.

-An interdisciplinary team (county social worker, teacher and parent) must develop an initial behavioral assessment. Annual assessments are conducted thereafter to measure the child's growth.

Appendix B. Comparison of Family Subsidy/Support Programs in Selected States

State	Administering Agency	Type of Program	Eligibility Criteria	Per Client/ Family Expense Limits	Number of Clients/Families Served FY 1978-79	Services Furnished Permissible Expenses	Total Program Appropriations Fiscal Year 1978-79
Florida	Retardation Program Office, Dept.of Health & Rehabilitation Services	Cash Subsidy	Borderline to Profoundly Retarded; no age restrictions	No limits; individually determined based on client needs (current range $30-$680 per mo.	43 (2/3's profound)	Ambulation Equipment; Respite Care;homemaker services;transportation; architectural changes in home;medication;parent training and counseling	$150,000
Minnesota	MR Division, Dept. of Public Welfare	Cash Subsidy	Children under 18,eligible for placement in a state institution or CRF* no family income restrictions.	Up to $250 per month	52;(25 multiply handicapped; 8 autistic)	Special equipment; medical services;special clothing; respite care; babysitting; supplemental education	$300,000 (FY 1977-79 biennium)
North Dakota	Community Services Division, Social Services Bd.	Cash Subsidy	No age restrictions; any DD person	Up to $50 per week	New program, 1st yr. projection: 23	Undetermined (Study under way)	$100,000

Appendix B. (continued)

State	Administering Agency	Type of Program	Eligibility Criteria	Per Client/ Family Expense Limits	Number of Clients/Families Served FY 1978-79	Services Furnished Permissible Expenses	Total Program Appropriations Fiscal Year 1978-79
ennsyl-ia	Office of MR, Dept of Public Welfare	Support Subsidy	Borderline to Profoundly retarded; no age restrictions	Individually determined based on client needs.	19,000	Respite care; babysitters; homemaker services; recreation programs; transportation in=home therapy; parent training and counseling	$3,500,000
Rhode Island	Division of Retardation; Dept of MH, Retardation & Hospitals	Cash Subsidy	No age restrictions; MR resident of state residential facility for over 90 days.	$4 - $75 weekly, depending on degree of disability	10	Basic care and training allowance for each MR client served; may be used according to parent discretion	$79,000

Appendix C. Fee Schedule

CLINTON-EATON-INGHAM
COMMUNITY MENTAL HEALTH BOARD
PROGRAMS FOR THE MENTALLY RETARDED

RESPITE CARE PROGRAM
FEE SCHEDULE

TAXABLE INCOME	RESPITE CARE DAILY RATE	PERCENTAGE PAID FOR SPECIAL NEEDS PURCHASES
$ 0 - $6,999	No Charge	0%
7,000 - 8,499	$ .50	5%
8,500 - 10,499	1.00	10%
10,500 - 11,499	1.50	15%
11,500 - 13,499	2.00	10%
13,500 - 14,999	2.50	25%
15,000 - 16,499	3.00	25%
16,500 - 17,999	3.50	30%
18,000 - 19,499	4.00	35%
19,500 - 20,999	4.50	35%
21,000 - 22,499	5.00	40%
22,500 - 23,999	5.50	45%
24,000 - 25,999	6.00	45%
26,000 and over	6.50	50%

This fee schedule is based on the Department of Mental Health's payment schedule in the Michigan Mental Health Code, April 1977, Chapter 8, section 330.1818.

Fees can be paid on an installment basis. All questions concerning billing and payment should be directed to the finance office, 300 North Washington Ave., Lansing, 48933. Telephone 374-8000.

1/79

Appendix D. Special Needs Purchases

Equipment

Ball	$79.00
Beanbag	$17.00
Bed Rails	$76.95
Feeding Spoons	$11.80
Feeding Spoon & plastic food guard	$8.35
Food Processors	$36.04
	$36.04
	$48.77
Gunnell bathchair	$212.90
	$215.40
	$189.60
	$199.10
Gunnell swing-seats	$510.10
	$410.60
	$504.80
	$493.80
Helmet	$19.00
Highchair	$34.99
Infant walker	$47.50
Locks and installation	$1,621.00
Reclining chair	$299.00
Safety Switches	$99.00
Sandbags	$40.00
Shoes	$32.00
	$37.50
Sling aid bath seat	$89.50
	$89.50
	$89.50
Swim Club	$184.00
Swing frame	$85.00
Tricycle	$144.50
Wedge	$18.50
Wedge & bolster	$113.75
Wedges	$114.00
Wheelchair parts and repair	$63.00

Services

Ambulance	$132.50
Camp	$85.00
Child care payment	$725.61
Family camp	$62.00
Family picnic	$51.00
Medication	$37.00
Physical Therapist	$60.00
Speech evaluation	$31.50
Visiting nurses	$285.00

Appendix E

COMMUNITY MENTAL HEALTH BOARD
Clinton - Eaton - Ingham

Programs For The Mentally Retarded

QUALITY OF LIFE QUESTIONNAIRE*

INTRODUCTION

Please take about thirty minutes of your time to answer the following questions. Your input will be used to help determine how our agency may best assist families in our community to care for their severely (SMI) or multiply impaired (SXI) children.

BACKGROUND INFORMATION

Your Name(optional)_____ Sex:_____ Age:_____

Do you have any handicapped children of your own? _____

Do you have any foster children who are handicapped? _____

If you answered "Yes" to either question, please answer the following:

If you answered "No" to both questons please turn to page 3.

	#1	#2	#3		#1	#2	#3
How many children?____Their ages:	___	___	___	Their sexes:	___	___	___

	#1		#2		#3	
Circle "O" for own or "F" for foster child:	O	F	O	F	O	F

Where do your children presently live?

	#1	#2	#3
At home	___	___	___
In a foster home	___	___	___
In an institution	___	___	___
Other _____	___	___	___

Over the last year, how many months did they live:

	#1	#2	#3
At home	___	___	___
In a foster home	___	___	___
In an institution	___	___	___
Other _____	___	___	___

*Adapted from: John C. Flannagan, "A research approach to improving our quality of life", *American Psychologist,* Feb., 1978, V33, N2, pp. 138-147.

Please describe their disabilities by checking the appropriate boxes.

LEVEL OF MENTAL RETARDATION

#1	#2	#3	
( )	( )	( )	No Retardation
( )	( )	( )	Borderline
( )	( )	( )	Mild
( )	( )	( )	Moderate
( )	( )	( )	Severe
( )	( )	( )	Profound
( )	( )	( )	Unknown

SPEECH DISORDER

#1	#2	#3	
( )	( )	( )	No Disorder
( )	( )	( )	Some Disorder
( )	( )	( )	No Speech
( )	( )	( )	Unknown

BEST VISION (w/correction, if needed)

#1	#2	#3	
( )	( )	( )	No impairment
( )	( )	( )	Moderate to Severe Impairment
( )	( )	( )	Legal Blindness
( )	( )	( )	Unknown

BEST HEARING (w/correction, if needed)

#1	#2	#3	
( )	( )	( )	No impairment
( )	( )	( )	Moderate to Severe Impairment
( )	( )	( )	Deafness
( )	( )	( )	Unknown

CONVULSIVE DISORDER (w/medication, if needed)

A. Present

#1	#2	#3	
( )	( )	( )	NO
( )	( )	( )	YES
( )	( )	( )	Unknown

B. Frequency of Convulsions

#1	#2	#3	
( )	( )	( )	Not applicable
( )	( )	( )	Several Daily
( )	( )	( )	Weekly
( )	( )	( )	Less than Weekly
( )	( )	( )	Unknown

MOTOR DYSFUNCTION

A. Present

#1	#2	#3	
( )	( )	( )	NO
( )	( )	( )	YES
( )	( )	( )	Unknown

B. Intensity

#1	#2	#3	
( )	( )	( )	Full Use
( )	( )	( )	Limited Use
( )	( )	( )	No Use
( )	( )	( )	Unknown

BEHAVIOR PROBLEMS

A. Present

#1	#2	#3	
( )	( )	( )	NO
( )	( )	( )	YES
( )	( )	( )	Unknown

B. If yes, briefly describe:

1. _____
2. _____
3. _____

OTHER DISABILITIES (Please describe)

#1. _____

#2. _____

#3. _____

INSTRUCTIONS

For each category, answer questions #1 and #2 by circling the letters along the borders that best describe how you feel. Answer questions #3 and #4 by writing down what you feel. The complete questions are provided in the QUESTIONS KEY. Thank you very much for your time.

QUESTIONS KEY

1. At this time in your life, how important to you is/are . . .?
   VI = Very Important; I = Important; MI = Moderately Important;
   SI = Only Slightly Important; or NI - Not At All Important.

2. How well are your needs and wants being met in this regard?
   VW = Very Well; W = Well; MW = Moderately Well;
   SW = Only Slightly Well; or NW = Not At All Well.

3. What things are *interfering* with your needs being met more fully?

4. What things would *help* you meet your needs more fully?

CATEGORIES

Question #1 Importance: Very Important ... Not Important

Question #2 Needs and Wants Being Met: Very Well ... Not Well

Physical and material well-being

VI I MI SI NI

A. *Material comforts*-things like a desirable home, good food, possessions, conveniences, an increasing income, and security for the future.

VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI

B. *Health and personal safety*-to be physically fit and vigorous, to be free from anxiety and distress, and to avoid bodily harm.

VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

Question #1 Importance: Very Important / Not Important

Question #2 Needs and Wants Being Met: Very Well / Not Well

Relations with other people

VI I MI SI NI

C. *Relationship with your parents, brothers, sisters, and other relatives*-things like communicating, visiting, understanding, doing things, and helping and being helped by them.

VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

We are particularly interested in your answers to the next category. First, answer questions #1 and #2 in terms of all of the children you may have.

VI I MI SI NI

D. *Having and raising children*-this involves being a parent and helping, teaching, and caring for your children.

VW W MW SW NW

Now, answer all four questions in terms of any handicapped and non-handicapped children you may have.

VI I MI SI NI

D-1. Handicapped Children

VW W MW SW NW

3. Things Interfering: _____

_____

_____

4. Things That Would Help: _____

_____

_____

VI I MI SI NI

D-2. Non-Handicapped Children

VW W MW SW NW

3. Things Interfering: _____

_____

_____

4. Things That Would Help: _____

_____

_____

Question #1 Importance		Question #2 Needs and Wants Being Met	
Very Important	Not Important	Very Well	Not Well

Relations with other people

VI I MI SI NI E. *Close relationship with a husband/wife/* a person of the opposite sex. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI F. *Close friends*-sharing activities, interests, and views; being accepted, visiting, giving and receiving help, love, trust, support, guidance. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

Social, community, and civic activities

VI I MI SI NI G. *Helping and encouraging others*- this includes adults or children other than relatives or close friends. These can be your own efforts or efforts as a member of some church, club, or volunteer group. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI H. *Participation in activities relating to local and national government and public affairs.* VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

Question #1 Importance		Question #2 Needs and Wants Being Met	
Very Important	Not Important	Very Well	Not Well

Personal development and fulfillment

VI I MI SI NI — I. *Learning,* attending school, improving your understanding, or getting additional knowledge. — VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI — J. *Understanding yourself* and knowing your assets and limitations, knowing what life is all about and making decisions on major life activities. For some people, this includes religious or spiritual experiences. For others, it is an attitude toward life or a philosophy. — VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI — K. *Work* in a job or at home that is interesting, rewarding, worthwhile. — VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI — L. *Expressing yourself* in a creative manner in music, art, writing, photography, practical activities, or in leisure-time activities. — VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

Question #1 Importance					Question #2 Needs and Wants Being Met				
Very Important				Not Important	Very Well				Not Well

Recreation

VI I MI SI NI M. *Socializing*-meeting other people, doing things with them, and giving or attending parties. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI N. *Reading, listening to music, or observing* sporting events or entertainment. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

VI I MI SI NI O. *Participation in active recreation*-such as sports, traveling and sightseeing, playing games or cards, singing, dancing, playing an instrument, acting, and other such activities. VW W MW SW NW

3. Things Interfering: _____

_____

4. Things That Would Help: _____

_____

At the present time, how would you describe your overall quality of life? (Circle One)

Excellent, Very Good, Good, Fair, Poor

Please use the space on the back of this page for any additional comments you wish to make. Thank you once again for your time.

Appendix F. Satisfaction Questionnaire

COMMUNITY MENTAL HEALTH BOARD
Clinton-Eaton-Ingham
PROGRAMS FOR THE MENTALLY RETARDED

Dear Parents, Home Operator(s):

Programs for the Mentally Retarded would like to know how satisfied you are with the services you have used and what you think could be done to improve them. Please answer the following items and return the questionnaire(s) to PMR in the pre-paid envelope. Couples are asked to complete two forms individually.

I. Check the services you have used and indicate your overall degree of satisfaction with them

Service	Used Yes	Used No	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatis.
Case Management	___	___	___	___	___	___	___
Counseling/Therapy	___	___	___	___	___	___	___
Emergency Respite Care	___	___	___	___	___	___	___
Family Friend Respite Care	___	___	___	___	___	___	___
Foster Respite Care	___	___	___	___	___	___	___
Home-Based Respite Care	___	___	___	___	___	___	___
Special Needs Purchases	___	___	___	___	___	___	___
All Services Used	___	___	___	___	___	___	___

II. How would you improve:

Case Management?_____

_____

Counseling/Therapy?_____

_____

Emergency Respite Care?_____

_____

Family Friend Respite Care?_____

_____

Foster Respite Care?_____

_____

Home-Based Respite Care?_____

_____

Special Needs Purchases?_____

_____

III. What services do you need that have not been available to you?_____

_____

IV. Other comments (If necessary, please use the back of this page):_____

_____ _____

APPENDIX G. Summary of Previous Project Issues

Issue	Summary	Action Taken
1) What population should this project serve?	The project was limited to SMI and SXI children initially for fiscal reasons. Questions arose about who fit the SMI-SXI categories. Autistic persons felt that they should be included. Requests have also been made to broaden the age and disability categories.	After consultation with local school officials and a review of Act 258, autistic persons were included in the project under its original population definitions.
2) Can respite care services be used while a parent is working?	Requests were made to use respite services to care for children while the parent worked. This was appealed by the parent task force.	An administrative decision was made that use of respite for work would be too costly over a long period of time and that it did not coincide with the philosophy of respite care being provided to allow a parent a rest from their child.
3) Can foster families participate in the family support project?	Foster families caring for SMI and SXI children requested services from the project. Task force members felt that this was contrary to the project's intent.	Issue was discussed at several task force meetings. A decision was made that foster families could participate based on the fact that these services would allow a child to stay in his/her home community.
4) Will the Family Support Project be continued beyond FY 78-79?	Department of Mental Health Regional Office instructed Community Mental Health to prepare a phase out plan in case the project is not refunded. Department of Mental Health Central Office staff have stated that the project will be continued. Task force members and Community Mental Health have requested that the project be continued.	Continuation requests have been made at legislative budget hearings. Department of Mental Health is completing budget guidelines which will be used to request continuation.

Appendix G. (continued)

Issue	Summary	Action Taken
5) Who owns equipment purchased with Special Needs funds?	Clarification was requested regarding equipment purchased with Special Needs funds.	Equipment will be the property of Community Mental Health.
, Can regular respite care be used by project participants?	Families were concerned that the respite care available through the project would not be adequate and wanted assurances that regular respite care would also be available to them. Community Mental Health staff have taken the position that the amount of respite available would be adequate.	The issue was discussed at several task force meetings. It was decided to monitor usage and make a decision based on usage patterns.
7) What is the eligibility for services and special needs for families whose handicapped children do not live in the home?	Parents of a child living in a community nursing home desires special needs purchases to meet child's needs during frequent home visits. Is this an appropriate utilization of Family Support Project funds?	It was decided the standard to be employed is whether purchases would be instrumental in maintaining child in the community and strengthening family relationships. If so, expenditure is appropriate.
8) What is an appropriate mechanism for maximizing the likelihood of a high level of quality in respite care?	Staff believes that variability in quality of respite care is too high. Families utilizing respite care were reulctant to bring up concerns of dissatisfaction at the time they take place.	Client feedback questionnaire is to be turned in monthly by each family for each respite home used that month. Questionnaire linked to verification of dates of care to maximize return date.
9) Is the existing recipient rights process adequate to serve a project like the Family Support Project?	A review of existing foster respite care homes and conversations with many families revealed that greater structure was needed to assure high quality care in homes used for respite care.	Family Support Project staff have reviewed recipient rights material with respite providers and increased their monitoring functions of individual homes.

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